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See the broader picture

Most conferences are organised by professional bodies. This meeting was an exception. Held in Edinburgh (2-3 April 2003) and attended by nearly 1000 delegates, it was driven by the concerns of parents and care-givers. For organiser Sofie Dow, Founder and Chairman of the special needs charity Mindroom (formerly Mindfield), is the parent of a teenage girl whose specific learning requirements were ill-adapted to the school system.

Dow, introducing, spoke of her 2020 dream. By that time, she hopes, all special needs children will have their disabilities assessed and dealt with. Her vision includes multidisciplinary 'one-stop' assessment centres where complex needs can be pinpointed immediately, and without years of delay as is the current system.

Baroness Linklater emphasised her outrage at the struggle of families to have their needs met. Also with an affected daughter, she spoke of how intervention unlocked skills she never knew her daughter had, assistance bringing marked improvement of mood and focus - she quotes her saying 'I have some sunshine in me now'. A reflection, she points out, of just how dark it was before her problem was addressed.

[Image] The problem is that you
clash with yourself

Thor Soltvedt, a Norwegian poet, read his own work describing the schooling of a young problem boy. On questioning about conflict within the school, Soltvedt observes the scene - 'The problem is, said the headmaster, that you clash with yourself', a sentiment that brought immediate resonance from the audience.

The meeting aimed to understand and deal with this clash. And a clash that is not purely internal, but equally between resources and needs, and to assemble all the pieces of the jigsaw into The Broader Picture, the title of the conference. To this end there was contrast and exchange between the problems of severe early childhood disorders, and their causes, and the particular difficulties of adolescents in mainstream or special education.

Special focus was placed on a cluster of overlapping conditions including attention deficit disorder (ADD) often with hyperactivity (ADHD), autism, dyslexia and dyspraxia. This summary covers some highlights.

KEYNOTE SPEECH

The keynote address was from Christopher Gillberg (Goteborg, Sweden). He underlined the demarcation between ADD, autism, Dyslexia/dyspraxia, and what he calls DAMP - deficits in attention, motor control and perception, partly spanning autism and ADD.

ADD-like conditions now affect 3-7% of children, and autistic spectrum disorders (ASD) including Asperger's 1%, with the difference that ADD children often get by in mainstream education, while classical autism, especially if untreated, requires special assistance.

He warned that, by tailoring intervention to the condition first diagnosed, this risks leaving other equally important problems unattended.

87% of ADD children have a second diagnosis, and 67% can have two or more additional diagnoses, including developmental coordination disorder (DCD), opposition defiant disorder (ODD), affective disorders, anxiety, depression, tics.

In autism, co morbidity includes ADHD, depression, anxiety, eating disorders [including anorexia], sleep problems, self-injury, explosive outbursts, and bipolar disorder.

This theme was reiterated by Alex Richardson (Oxford) who spoke of fragmentation of the support provided.

A child first diagnosed as dyspraxic might only receive physiotherapy, while diagnosis of ADD might lead exclusively to assistance from educational psychologists. This 'first past the post' approach ignores the co morbid conditions that the vast majority of affected children suffer from.

Gillberg reviewed the origins and causes of these disorders. Genes make a strong contribution, with 64-91% of the variance in ADHD being explained by

genetic factors; a similar contribution is found in autism. He noted that 10% of Down's syndrome (trisomy 22) children can fulfil the criteria of autism.

In autism, siblings have an elevated risk of developing the disorder, estimated at 3-5% depending on diagnostic criteria, but he noted that first degree relatives often have a 'broader phenotype', with anxiety, social phobia, and obsessive-compulsive disorder being more frequent than in the general population.

Nevertheless, environmental factors can be triggers - he mentioned striking cases where autism onset occurred in otherwise healthy individuals, 14 or 31 years of age at the time, following herpes encephalitis.

The brain regions affected in autism are not known, but Gillberg included the amygdala, hippocampus, pons and cerebellum as candidates, though brainstem damage is suggested by facial nerve immobility, decreased postrotatory nystagmus (continued eye movement after a period of brisk turning), and abnormal auditory brainstem responses.

He noted major improvements in autism when a strong psycho educational environment is provided, and how anxiety and self-harm are reduced markedly in 'autism-know-how' environments skilled in accommodating autistic children.

Several speakers felt that labels like ADD and ASD (autistic spectrum disorder) are essential - even though they can be imprecise. Diagnosis is for many people the most important part of the treatment plan. Even so, Gillberg made a strong point: it would be insulting to use the term 'pneumonist' to describe someone with pneumonia; terms such as 'autist' are unacceptable. Conversely, for a child to be able to say, 'I've got ADD or Asperger's', clearly contributes towards acceptance and behavioural therapy.

Svenny Kopp, also from Goteborg, discussed the under-reporting of girls with ADD. Classically, the incidence is three-fold higher in boys than in girls, but she has discovered that the prevalence in girls is just as high as in boys, but is not recognized.

Boys show their frustration and distress, girls tend to be more compliant, concealing their condition, but suffering no less. In her researches she says 'the teachers did not understand why researchers were examining their girls'.

[Image] ADD in girls is just as high as boys but not recognised

Speaking of double diagnosis, she said that 80% of ASD girls also met the diagnostic criteria for ADHD. She made an insightful observation - that behavioural deficiencies change and evolve with age. This was illustrated by one case, 'Susan' (not her real name). In utero her mother reported she was unusually active. During the first year she had depressed eye contact. At three years she had screaming fits that could last 1-2 hours, though these then stopped. At 14 she had memory problems, easily losing personal belongings, and being unable to remember what the teacher had said. Diagnosis should be flexible to allow for evolution over the course of time.

Thomas Brown (Yale University) stressed that many of the deficits of ADD, and perhaps autism, point to a problem of executive function - the higher brain centres that determines what we decide to do, and when. These children have difficulties in organising tasks, and intrusive emotions are all too powerful. Often, they have impaired ability to inhibit inappropriate actions, and the perception of time duration is affected.

[Image] I can't remember what the teacher just told me

He divided executive function into six categories, including activation, focus, effort (regulation of sleep/alertness), emotion, memory and final action. Attention deficit children and adults have difficulty organizing tasks, and estimating time, and often have a difficulty in initiating activity.

Because executive function develops with time, deficits associated with slow development are often not seen before age seven. He suggested that damage restricted to one side of the brain might produce the milder and high-performing form of autism - Asperger's syndrome - but classical autism ensues when damage is bilateral.

[Image]

He emphasised the impact of memory problems - 'I can't remember what the teacher just told me' said one boy. Apparent attention deficit may have several causes. Medication -- Ritalin, antidepressants and the newer Strattera (not yet available in the UK) - improves the outcome for 80% of ADD children, and should be considered, even in adults. Gillberg cites the resistance of medical practitioners - 'I'll believe in ADD when there's a blood test', he quoted one GP as saying, despite a memorandum from a consortium of eminent researchers published recently with the message 'it's real, it must be recognized'.

[Image] Dietary deficiencies are common, including essential fatty acids (particularly EPA)

The message of some speakers was 'it's not just a brain disorder'. Alex Richardson (Oxford) pointed to allergies and immune problems, digestive, sleep and perceptual difficulties. She focused on common features between dyslexia, dyspraxia, ADD with hyperactivity, and autism.

Association with early insult (during gestation and the perinatal period), the excess of affected males, the autoimmune and digestive problems, affective disorders including stress susceptibility, sleep difficulties, and perceptual/cognitive abnormalities (visual, auditory, attention, memory).

These common features may all be causally associated with dietary factors. She pointed out that Mankind grew up with a diet rich in fish, nuts and green vegetables, items not favoured by children today. Dietary deficiencies are common, including essential fatty acids (particularly 'EPA').

A study from Hackney, London, has revealed that up to 10% of neonates suffer from significant nutritional deficiency.

She felt that deficiencies of EPA in particular may contribute to dyslexia, dyspraxia, autism and attention deficit, but also to disorders as diverse as depression, bipolar illness and schizophrenia.

A double-blind study of asocial behaviour recently demonstrated a marked improvement in offenders receiving dietary supplements. In dyspraxia, EPA replacement (with cod liver and evening primrose oils) had brought amazing improvement in many children studies are underway for other related disorders.

She listed other potential contributors including zinc deficiency, toxic metals, and organics including pesticides and artificial food additives. In a DEFRA-funded study, she reported, a combination of five common additives was found to degrade behaviour significantly in all children studied, and not just a sensitive subgroup.

Attention was drawn to other diet-related factors, including intolerance to dairy produce and wheat (anti-gliadin antibody, a sign of wheat intolerance, being detected in 1/150 of the population), to lactose (up to 20% of the European population being unable to degrade this sugar) and overgrowth of gut flora, particularly yeast.

She expressed her concern at the resistance shown by the authorities to the idea that diet might affect the brain. As she said, it is widely accepted that proper nutrition of a pet restores the sheen to its coat and good humour to its behaviour, but she found it incomprehensible that the same idea is not accepted when applied to a child.

She confessed that one dietary remedy she is employing derives from the veterinary literature - where the link between diet and behaviour is well established.

Loretta Giorcelli (Sydney, Australia) made the point that there is a problem convincing educators (and parents) to be tolerant of children who do not easily fit in. Too often, teachers respond in kind to the difficult child, resulting in a stand-off that 'teacher cannot win'. The most brilliant educators devised ways of incorporating difficult charges into the normal framework, for instance by devising a 'cooling-off' period after breaktime.

She spoke of the need to reinterpret children's protests. The child who says 'it's boring' or employs diversionary tactics may often mean 'I just don't know how to get started'.

Social pressures in the classroom can also be severe - avoidance, disruption and diversionary tactics may be driven by fear of embarrassment; some affected pupils have spoken of constant public humiliation. Dealing with this social factor can relieve disruptive behaviours.

Giorcelli also advocated the need to value and support unobtrusively these children, to avoid ridicule, and to acknowledge positive compliance. She warned of Mother Theresa syndrome, where problem children are sometimes expected to attain a perfection of behavioural compliance that any normal child would find impossible.

Fair and open dealing with pupils, in open consultation, was necessary. 'Fairness', she quotes Socrates, 'is giving everyone what they need'.

Too often, she felt, schools were reluctant to change rigid and inflexible practices. She spoke of contradictory attitudes - one school in the south was considering bringing in a 'zero-tolerance' clampdown, the worst of all policies she felt, while in the north of the country schools were attempting to bring in a flexible and accommodating approach - 'restorative justice' - pioneered in New Zealand with outstanding results.

[Image] Fairness is giving everyone what they need

[Image] The UK lacks joined-up services

Other sessions from top contributors dealt with the diversity of childhood neuro-developmental disorders, the role of non-verbal communication, and how best to deal with the specific problems of adolescents in and outside school.

Nina Black (Sweden), herself affected by DAMP, explained what it felt like. In her 30s she confessed that she could get along fine but only with help, and positive motivation.

Ken Aitken (Edinburgh), summed up. 'If this meeting had been held 10 years ago the response would have been incredulous -the disorders were considered to be extremely rare'. But not now. Thomas Brown (Yale) emphasised that with proper support these individuals can do extremely well, citing the chief executive of a multinational company and a US president. More professional training for diagnosis and ongoing intervention at all levels is required, he says.

The UK lacks joined-up services, said another speaker, while Goldstein (Utah) felt the challenge will be to plan ahead on a sound scientific basis. In doing so the authorities should be ready to take up and apply recent research results, even though there is often hostility to change. Affected individuals should be listened to carefully, and their diversity recognised. Autistic or ADD children are individually as different as the members of any other group - red-heads, Scots, or boys.

This was a wide-ranging conference befitting its title 'The Broader Picture'. The take home message was that medical and behavioural interventions whose efficacy has been demonstrated are not used nearly enough.

Services are sometimes 'fragmented', and authorities resistant to change. Research is now producing new insights; but half of the battle will be to put new strategies into practice. Nina Brown's final message was - 'don't give up'.